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Report of the United Nations High Commissioner for Human Rights*

Summary

In the present report, submitted pursuant to General Assembly resolution 48/141, the United Nations High Commissioner for Human Rights examines how the human rights framework, particularly the rights to health and to social security, can contribute to the conceptualization of universal health coverage and to its implementation. The report outlines some of the key human rights challenges of extending universal health coverage, such as access to medicines, deficits in the health work force, the impact of corruption and the very sizeable populations and groups who have been excluded from health coverage. The High Commissioner concludes that universal health coverage must, in keeping with the character of the right to health as an inclusive right encompassing service delivery and the underlying determinants of health, be understood to incorporate effective access and other determinants of health, as well as formal coverage.

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I. Introduction

1. In October 2018, Heads of State and Government convened in Astana to reaffirm the commitments contained in the Declaration of Alma-Ata, adopted at the International Conference on Primary Health Care in September 1978, and in the 2030 Agenda for Sustainable Development. The outcome was the Declaration of Astana, in which States committed to “pursue [a path] to achieving [universal health coverage] so that all people have equitable access to the quality and effective health care they need, ensuring that the use of these services does not expose them to financial hardship”. On 23 September 2019, the General Assembly will hold, pursuant to its resolution 72/139, a high-level meeting on universal health coverage. The meeting is an extraordinary opportunity for Member States to develop a road map to universal health coverage, which is firmly anchored in the rights to health, social security and other health-supporting rights. The United Nations High Commissioner for Human Rights stresses that it is imperative for States to integrate human rights into their discourse and policy on universal health coverage if the millions who have been left behind are at last to be accorded their rights along with others.

2. Having first been recognized internationally in the Constitution of the World Health Organization (WHO) in 1946, the right to health is articulated most exhaustively in article 12 of the International Covenant on Economic, Social and Cultural Rights, in which States parties to the Covenant recognize the right of everyone to the highest attainable standard of physical and mental health. The right to health is also guaranteed in the Universal Declaration of Human Rights and in other human rights treaties at the global and regional levels.¹ In the context of access to medicines, health technologies and therapies, the right to enjoy the benefits of scientific progress and its applications,² with its emphasis on the accessibility of innovations essential for a life with dignity, is particularly relevant (see A/HRC/20/26, para. 29).

3. Another right that is instrumental to the achievement of universal health coverage – the right to social security, including social insurance – is similarly protected under the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Persons with Disabilities, the Universal Declaration of Human Rights and other instruments. The International Labour Organization (ILO) has developed a comprehensive body of norms on social protection. These include the Social Security (Minimum Standards) Convention, 1952 (No. 102), the Medical Care and Sickness Benefits Convention, 1969 (No. 130), and the accompanying Medical Care and Sickness Benefits Recommendation, 1969 (No. 134), the Medical Care Recommendation, 1944 (No. 69) and the Social Protection Floors Recommendation (2012) (No. 202). These standards have the aim of achieving “universal health protection based on guaranteed access to health care for all in need through at least essential health care, prevention and maternal care”.³

4. Much of the discussion of the content of universal health coverage has been from perspectives other than human rights. Consequently, the principal objectives of the present report are to assess the contribution that a human rights framework can make to the conceptualization and implementation of universal health coverage and to highlight key human rights principles that should guide public health policy in this area. The High Commissioner outlines major human rights dimensions relating to health coverage – of which inequality is a cross-cutting one – and makes several corresponding recommendations.

¹ See the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child, the Convention on the Rights of Persons with Disabilities, the African Charter on Human and Peoples’ Rights, the European Convention on Human Rights and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights.

² See the Universal Declaration of Human Rights, art. 27 (1) and the International Covenant on Economic, Social and Cultural Rights, art. 15 (1) (b).

³ ILO, *World Social Protection Report 2017–19: Universal social protection to achieve the Sustainable Development Goals* (Geneva, International Labour Office, 2017), p. 102.

II. Health and sustainable development

5. Healthy societies constitute the bedrock of sustainable development, and poor health outcomes have a direct impact on the ability of a community to flourish and build resilience. Non-communicable diseases, for instance, are responsible for 41 million deaths every year, or 71 per cent of all deaths globally. Some 15 million deaths are reported in the 30 to 69 years age group, affecting a substantial proportion of the work force.⁴ WHO estimates that one person in four will experience mental or neurological conditions during their lifetime.⁵ With approximately 450 million people affected worldwide, the global economic loss attributable to poor mental health outcomes as people are forced out of employment and into poverty currently stands at some 1 trillion dollars a year.⁶ Health care, more than any other component of social protection, is indispensable to the economy as a whole, and to economic recovery in particular.⁷

6. The States Members of the United Nations recognized the connection between health and development in the 2030 Agenda for Sustainable Development, which envisages “a world with equitable and universal access to quality education at all levels, to health care and social protection, where physical, mental and social well-being are assured”. The 2030 Agenda places emphasis on equality, and the commitments to leave no one behind and to reach first those who are furthest behind are founded on the human rights principles of equality and non-discrimination, and of prioritizing the vulnerable and marginalized in society.

7. Universal health coverage falls specifically under Sustainable Development Goal 3 (ensure healthy lives and promote well-being for all at all ages), with target 3.8 specifying financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all as elements of universal health coverage. As the Sustainable Development Goals are “integrated and indivisible”, other goals are relevant to universal health coverage: Goal 1 sets out a commitment to ending poverty in all its forms everywhere, with target 1.3 aiming at the implementation of nationally appropriate social protection systems and measures for all, including floors, and the achievement, by 2030, of substantial coverage of the poor and the vulnerable. Goal 10 aims to reduce inequality within and among countries, and target 10.4 (adopt policies, especially fiscal, wage and social protection policies, and progressively achieve greater equality) addresses several enablers of universal health coverage. Gender equality, a major determinant of health, is covered by Goal 5 (achieve gender equality and empower all women and girls), and related targets aim, among other objectives, to end discrimination, eliminate violence against women and girls and end harmful practices, such as female genital mutilation and child, early and forced marriage.

III. Understanding universal health coverage

8. A broadly accepted definition of universal health coverage is yet to be developed. Nevertheless, stakeholders involved in promoting universal health coverage, particularly Member States and normative organizations, such as WHO and ILO, have helped to clarify applicable norms and to identify its technical content and other elements. Human rights principles also provide guidance on universal health coverage (see paras. 32–45 below).

9. Although “universal health coverage” as a term is absent from the Declaration of Alma-Ata, the Declaration broke new ground in identifying primary health care as fundamental to attaining health for all. Article VI of the Declaration describes primary health care as “essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can

⁴ See www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases.

⁵ See www.who.int/whr/2001/media_centre/press_release/en/.

⁶ See www.who.int/mental_health/evidence/atlas/atlas_2017_web_note/en/.

⁷ ILO, *World Social Protection Report 2014/15: Building economic recovery, inclusive development and social justice* (Geneva, International Labour Office, 2014), p. 100.

afford to maintain at every stage of their development”. The Declaration of Astana, in its article II, affirms that strengthening primary health care is the most inclusive, effective and efficient approach to enhance people’s physical and mental health, as well as social well-being, and that primary health care is a cornerstone of a sustainable health system for universal health coverage.

10. Since 2008, the General Assembly has adopted an annual resolution on global health and foreign policy. In its resolution 67/81, adopted in 2012, in particular, the Assembly devoted considerable attention to universal health coverage, which implies that all people have access, without discrimination, to nationally determined sets of the needed promotive, preventive, curative and rehabilitative basic health services and essential, safe, affordable, effective and quality medicines. At the same time, the use of these services should not expose users to financial hardship, and special emphasis should be made on the poor, vulnerable and marginalized segments of the population. In its resolution 72/139, the Assembly reiterated these dimensions, adding palliative care to the package of basic health services. It encouraged Member States to promote the effective, full and meaningful participation of all, in particular those who are vulnerable or in vulnerable situations, in the design, implementation and monitoring of law, policies and programmes for health, including strategies for universal health coverage.

11. In their joint Global Monitoring Report (2017), WHO and the World Bank affirmed that universal health coverage meant that all people receive the health services they need, including public health services designed to promote better health (such as anti-tobacco information campaigns and taxes), to prevent illness (such as vaccinations) and to provide treatment, rehabilitation and palliative care (such as end-of-life care) of sufficient quality to be effective, while at the same time ensuring that the use of these services does not expose the user to financial hardship.⁸ Three related objectives are encompassed in such a definition: “equity in access to health services”, good quality; and protection against financial risk.⁹

12. In terms of linking universal health coverage and social protection, ILO has contributed a significant body of evidence-based normative and policy guidance for stakeholders, the foundational principle being that universal health coverage is an integral part of the minimum social protection guarantees that should be accessible to all. Universality of health coverage implies that, “in all countries, rights-based approaches, anchored and framed in legislation, should exist to cover the whole population, including workers in the formal and informal economy and their families”. Under this paradigm, the implementation and enforcement of these approaches are a prerequisite for access to health care.¹⁰

13. The ILO Social Protection Floors Recommendation (2012) (No. 202), articulating its human rights underpinnings through a clear recognition of the interdependence between health and social protection, encourages States to establish and maintain social protection floors comprising basic social security guarantees. At a minimum, these social protection floors should comprise basic social security guarantees, including (a) access to a nationally defined set of goods and services, constituting essential health care, including maternity care, that meets the criteria of availability, accessibility, acceptability and quality; (b) basic income security for children, at least at a nationally defined minimum level, providing access to nutrition, education, care and any other necessary goods and services; (c) basic income security, at least at a nationally defined minimum level, for persons in active age who are unable to earn sufficient income, in particular in cases of sickness, unemployment, maternity and disability; and (d) basic income security, at least at a nationally defined minimum level, for older persons.¹¹

14. The high-level commission convened by the Pan American Health Organization in 2017 to address universal health recognized primary health care “as a necessary and sustainable path towards the achievement of universal health”.¹² It stressed the significance

⁸ WHO, World Bank, *Tracking Universal Health Coverage: 2017 Global Monitoring Report*, p. xii.

⁹ See www.who.int/health_financing/universal_coverage_definition/en/.

¹⁰ ILO, *World Social Protection Report 2014/15*, p. 102.

¹¹ *Ibid.*, annex.

¹² Pan American Health Organization, *Universal Health in the 21st Century: 40 Years of Alma-Ata*, report of the High-Level Commission (Washington, D.C., Pan American Health Organization, 2019), p. 3.

of the “social inequality matrix” in acknowledging inequality as a “historic and structural characteristic” of societies in the region and identifying “elements that shape the circumstances of people’s lives”. Its report therefore embraces an understanding of “universal health” that comprises equitable access to health and to quality, comprehensive health services, as well as population coverage.¹³

IV. Relevance of the human rights framework

15. The human rights framework is indispensable for the formulation, implementation, monitoring and review of strategies for universal health coverage for a number of reasons:

(a) In the Charter of the United Nations, Member States reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small. The human rights treaties referred to above, and many others concluded over the years, elaborate on the content of those rights and underscore their universality. Human rights norms and standards are therefore binding legal obligations rather than mere policy choices.

(b) The use of a human rights framework and language is transformative. The Special Rapporteur on human rights and extreme poverty noted that human rights provide a context and a detailed and balanced framework; they invoke the specific legal obligations that States have agreed upon in the various human rights treaties; they emphasize that certain values are non-negotiable; they bring a degree of normative certainty; and they bring into the discussion the carefully negotiated elaborations of the meaning of specific rights that have emerged from decades of reflection, discussion and adjudication (A/70/274, para. 65). These elements are crucial for policy coherence and are a touchstone for directing effort and evaluating results.

(c) A human rights framework has the aim of rectifying power imbalances that distort health outcomes. As demonstrated in many situations where access to the health system is restricted – or interactions with it are difficult – unjust power relations ultimately have a significant influence on health outcomes. Mental health, for instance, is an area where power differentials between rights holders and health service providers play a pivotal role in access to and the quality of health care and services, the result being a much reduced life expectancy for those affected than for the general population.¹⁴ Given the rise of the private sector as an influential financial and political actor with the ability to challenge State power at both the global and national levels, human rights principles are vital for the protection of health-related rights.

(d) The protection of vulnerable and marginalized persons in society is a distinguishing preoccupation of human rights. Its message is one of equality and non-discrimination, inclusiveness and participation, and dignity and justice. As evidence shows, those most often excluded from health coverage tend to belong to populations and groups living in situations of marginalization or subject to discrimination. These populations and groups will also tend to be disproportionately exposed to health hazards, such as inadequate housing and sanitation in slums or indoor air pollution from combustible fuels. Incorporating human rights principles and norms into the conceptualization and implementation of universal health coverage would engage with and provide solutions for the multifaceted challenges of discrimination and exclusion.

V. Key human rights challenges to extending health coverage

16. The fundamental premise – and promise – of universal health coverage is equality; however, millions of people are routinely excluded from health coverage as a result of a combination of factors, including the commodification of health care, the underfunding of

¹³ Ibid., pp. 4 and 9.

¹⁴ Royal College of Psychiatrists, “Whole-person care: from rhetoric to reality. Achieving parity between mental and physical health”, occasional paper OP88, March 2013, p. 27.

the health sector, poor prioritization, discrimination and poverty. In the section below, the High Commissioner considers specific challenges that demonstrate the need for human rights in health coverage if it is to be truly universal.

A. Overarching challenges

17. More than half of the global population lacks access to adequate essential health care, such as prenatal care and the most basic treatment against malaria, HIV/AIDS and tuberculosis.¹⁵ There are wide disparities between regions and populations: 56 per cent of the global rural population (with Africa representing the greatest proportion), compared to 22 per cent of the urban population, lack health coverage.¹⁶ Populations in low-income countries have less ready access to essential health services; in fact, WHO recently confirmed that indicators, such as skilled birth attendance, women who have their need for family planning satisfied with modern methods of contraception, and immunization coverage, are also lower.¹⁷ A clear indicator of deficits in health coverage, catastrophic health expenditure affects a larger proportion of the population in middle-income countries than in low- or high-income countries.¹⁸

18. Although financial barriers are significant, socioeconomic determinants of health, such as inequality, discrimination and poverty, are major causes of exclusion from access to good quality health care and services on an equal basis with others. For affected populations and groups, social and economic exclusion is frequently aggravated by the contemporaneous impact of multiple intersecting forms of discrimination, which may be based on age, gender, ethnicity, migration status, sexual orientation, disability or health status and be perpetuated through harmful gender, cultural or social norms, and stigma. Inequality breeds disenfranchisement, restricts the enjoyment of other human rights and locks people into a dynamic of poverty, diminished opportunity, ill-health and shorter lifespans. The high-level commission (see para. 14 above) identified a configuration of social determinants characterized by “the emergence and consolidation of an economic model based on globalization and an expansion of the private sector, with increasing commercialization of living conditions and greater demographic urbanization”, the consequences of which include environmental deterioration, environmentally unsustainable conditions and climate change.¹⁹

19. The High-level Working Group on the Health and Human Rights of Women, Children and Adolescents, established in May 2016 by joint initiative of the Office of the United Nations High Commissioner for Human Rights (OHCHR) and WHO, found that, “against a backdrop of rising nationalism, the marginalization of millions of people, including undocumented migrants, refugees, slum dwellers and indigenous peoples, proceeds hand in hand with violations of their rights, escalating individual and public ill-health, and thereby undermining stability for entire societies”.²⁰ The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health observed an accelerating trend towards applying and justifying a narrow and selective approach to human rights that calls into question the very essence of human rights principles and standards (A/HRC/29/33). In making the case for health protection that is rights-based and not merely a privilege of the wealthiest, ILO refers to a global health crisis characterized by “the missing right to health”.²¹ The result of the interplay between all of these factors has been a failure to integrate human rights adequately into health policy development, implementation monitoring and review, including in relation to universal health coverage.

¹⁵ See [www.who.int/news-room/fact-sheets/detail/universal-health-coverage-\(uhc\)](http://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc)).

¹⁶ ILO, *Universal social protection for human dignity, social justice and sustainable development*, International Labour Conference (Geneva, International Labour Office, 2019), para. 101.

¹⁷ WHO, *World Health Statistics Overview 2019: Monitoring Health for the SDGs*, 2019, p. 8.

¹⁸ *Ibid.*

¹⁹ *Ibid.*, p. 8.

²⁰ WHO, *Leading the realization of human rights to health and through health: report of the High-Level Working Group on the Health and Human Rights of Women, Children and Adolescents* (2017), p. 7.

²¹ ILO, “Addressing the Global Health Crisis: Universal Health Protection Policies”, Social Protection Policy Papers, 2014, p. 2.

B. Access to medicines

20. Almost 2 billion people worldwide have been denied their right to enjoy the benefits of scientific progress and its applications owing to a lack of access to essential medicines.²² With regard to HIV/AIDS, for instance, 36.9 million people globally were living with HIV in 2017 and only 21.7 million of them had access to antiretroviral therapy. During the same period, 20 per cent of pregnant women living with HIV lacked access to antiretroviral medicines to prevent mother to child transmission of HIV.²³ Statistics compiled by the United Nations Children’s Fund (UNICEF) indicate that, of the 1.8 million children living with HIV globally, only 52 per cent are receiving antiretroviral therapy.²⁴ According to research conducted by the Joint United Nations Programme on HIV/AIDS (UNAIDS), while the global incidence of HIV infection declined by 25 per cent between 2010 and 2017, the incidence among people who inject drugs and their partners is rising. Tuberculosis and viral hepatitis infection rates are high in this population, and low levels of investment have led to poor coverage in harm reduction services, such as needle-syringe programmes, drug dependence treatment, overdose prevention, and testing and treatment for HIV, tuberculosis and hepatitis B and C.²⁵

21. One major barrier to access to medicines is excessive cost, keeping essential medicines, therapies and technologies out of reach for many.²⁶ Implicated in the cost equation is the failure of government policy, particularly with regard to the regulation of private sector involvement in impeding or facilitating access, inadequate support for the development of medicines and health technologies that cannot deliver high returns on the market, and the “overreach of intellectual property protections”, which hinders the production and distribution of low-cost generic drugs.²⁷

C. Health workforce

22. A skilled, effective and motivated work force, available in sufficient numbers to meet need, is indispensable to the achievement of universal health coverage. It has been estimated that, as at 2017, only half of all countries had the health-care workers required to deliver quality health care (estimated at 30 physicians, 100 nurses or midwives, and 5 pharmacists per 10,000 people).²⁸ In this area, too, disparities exist in and between countries and even between types of health services.²⁹ Countries in sub-Saharan Africa, South-East and South Asia, and some countries in Oceania are experiencing the greatest shortfalls; in some cases, more than 80 per cent of the population lacks access to health care and related services owing to health worker shortages.³⁰ The impact of health worker shortages is increasingly critical for older persons, more than half of whom have no access to long-term care.³¹

23. Unfavourable working conditions that fail to attract and retain skilled health and care workers are partly responsible for health worker shortages. The right of health and care workers to just and favourable conditions of work, including fair wages and safe and healthy occupational conditions, is protected under international law. In the health sector, as in others, poor working conditions tend to drive away the most skilled and competent workers, which in turn creates the conditions for corruption to thrive. Health and care worker migration, another consequence of the denial of rights at work, is known to affect countries in the “global

²² WHO, “Access to medicines: making market forces serve the poor”, 2017, p. 14.

²³ See www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf.

²⁴ See <https://data.unicef.org/topic/hivaids/paediatric-treatment-and-care/>.

²⁵ See statement made on 28 April 2019 by the United Nations High Commissioner for Human Rights at the Harm Reduction International Conference 2019, available at www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=24529&LangID=E.

²⁶ See www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_en.pdf.

²⁷ Global Commission on HIV and the Law, *HIV and the Law: Risks, Rights & Health*, July 2012, p. 8.

²⁸ “GBD 2017: a fragile world”, *Lancet*, vol. 392, No. 10159 (10 November 2018), p. 1683.

²⁹ See WHO, *World health statistics overview 2019*, p. 8.

³⁰ “GBD 2017: a fragile world”, *Lancet*.

³¹ ILO, *World Social Protection Report 2017-19*, p. 109.

South” more profoundly as health workers leave to seek more lucrative employment elsewhere.

D. Groups in focus

1. Persons with disabilities

24. One billion people worldwide are estimated to be persons with disabilities, and this figure is expected to rise.³² Owing to discrimination and social exclusion, they are at greater risk of poor health and therefore more likely to require and use health care and services (A/73/161, para. 5). Persons with disabilities are, however, also more likely to encounter barriers due to lack of accessible communications, information, equipment, environment and transportation to or from health facilities; restricted access to the full range of services they require, such as rehabilitation and assistive devices; and lack of respect for their right to free and informed consent.

25. Furthermore, on account of pre-existing health conditions, persons with disabilities face exclusion from health insurance and are less likely to benefit from work-related health insurance schemes.³³ As a result, persons with disabilities are 50 per cent more likely to experience catastrophic health expenditure, which pushes them into poverty, and has a direct impact on their rights to education, livelihood and participation in society.³⁴ To address this situation, States should ensure that universal health coverage includes the full range of health services that persons with disabilities may need as components of essential health services, including rehabilitation and assistive devices, as proposed by WHO in its priority assistive products list.³⁵

2. Migrants

26. Access to health care and services is a challenge for migrants in countries of transit and destination owing to the lack of legal protection for their right to health, laws or administrative regulations specifically denying them access to health care, cultural and linguistic barriers and, in the case of migrants in an irregular situation, fear of detention or deportation.³⁶ Migrants are often required to pay for medical services at the point of service because of their nationality or immigration status. Moreover, while in many countries emergency care cannot be refused, in others, migrants in an irregular situation are either excluded from any service or still expected to pay the full cost after treatment, which may discourage them from seeking treatment.³⁷

27. Migrants in vulnerable situations may experience poor mental health outcomes owing to the numerous hardships they face as a result of precarious and unsafe living and working conditions, social isolation and serious human rights violations suffered along migratory routes. Access to health care and services beyond emergency treatment is often dependent on proof of status, such as evidence of legal residence, insurance or employment, thereby excluding the vast majority of migrants in an irregular situation. Migrants in transit may be unable to have access to health care owing to the lack of medical staff and equipment along migratory routes or at international borders, and to policies that criminalize or deter irregular migration by threatening migrants with arrest, detention or deportation, effectively pushing migration underground. Migrants will often interrupt or delay vaccination, including of children born during the journey, out of fear of immigration enforcement at points of medical service or pressure to continue their journey. In both transit and destination countries, migrants in an irregular situation are frequently excluded from immunization as a consequence of their status, or lack of financial resources or information.

³² WHO, World Bank, *World Report on Disability* (2011), pp. xi, 21–31.

³³ See Lena Morgon Banks and Sarah Polack, *The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities: Evidence from Low and Middle Income Countries*, 2014.

³⁴ WHO, World Bank, *World Report on Disability*, pp. 66–69.

³⁵ See www.who.int/phi/implementation/assistive_technology/EMP_PHI_2016.01/en/.

³⁶ OHCHR, *The Economic, Social and Cultural Rights of Migrants in an Irregular Situation*, 2014, p. 10.

³⁷ *Ibid.*, p. 42.

3. Persons living with rare diseases

28. Between 300 and 400 million people worldwide live with rare diseases,³⁸ which are defined in the European Union as diseases affecting not more than five people in 10,000.³⁹ Half of those affected are children, and 30 per cent die before the age of 5 years.⁴⁰ Although individual diseases will typically affect small populations, the total number of people living with rare diseases amounts to approximately 4 per cent of the global population. As most rare diseases are complex, chronic, degenerative and frequently life-threatening, access to affordable, good quality and physically accessible health care and services, including long-term care, is essential.⁴¹ With treatment options available for only 5 per cent of rare diseases, they are largely neglected; market and public policy failures account in considerable measure for this.

29. Even when access to some form of health care exists, coverage usually mirrors health issues as experienced by the general population, with little or no attention paid to the specific needs and rights of persons living with rare diseases. According to the European Medicines Agency, fewer than 1,000 diseases benefit from even minimal amounts of scientific knowledge; the paucity of medical and scientific knowledge about rare diseases drives this marginalization, with the result that many people remain undiagnosed and therapies are difficult to develop.⁴² Consequently, the availability of health care and services remains low and their quality poor, especially with regard to associated impairments. Rare diseases often attract stigma and discrimination, and many persons living with a rare disease find themselves excluded from participation in employment and from integrating fully and productively into society.

E. Corruption

30. Corruption has been described as “one of the major obstacles to the effective promotion and protection of human rights”.⁴³ In addition to its negative effect on the ability of States to mobilize the maximum of available resources for the delivery of services essential for the realization of economic, social and cultural rights, corruption leads to discriminatory access to public services in favour of those able to influence authorities through methods including bribery and political pressure.⁴⁴ Corruption not only diverts scarce resources from where they are most needed but also distorts policy, weakens public trust in the health system and, ultimately, undermines efforts to deliver universal health coverage.⁴⁵

31. Corruption is pervasive in the health sector for a number of reasons: power asymmetries, including between health-care provider and patient and between government, the private sector and rights holders; the uncertainty inherent in selecting, monitoring, measuring and delivering health-care services; and the complexity of health systems (A/72/137, para. 16). The involvement of multiple parties ranging from policymakers to suppliers and doctors is a complicating factor that raises the prospect of “innumerable clandestine transactions of a corrupt nature among various stakeholders”.⁴⁶ Corruption takes

³⁸ See IFPMA, *Rare Diseases: shaping a future with no-one left behind*, 2014; available from www.ifpma.org/wp-content/uploads/2017/02/IFPMA_Rare_Diseases_Brochure_28Feb2017_FINAL.pdf. See also <https://globalgenes.org/wp-content/uploads/2015/12/2016-WRDD-Fact-Sheet.pdf>.

³⁹ See IFPMA, *Rare Diseases*.

⁴⁰ See <https://globalgenes.org/wp-content/uploads/2015/12/2016-WRDD-Fact-Sheet.pdf>.

⁴¹ See Rare Diseases International, “Rare Diseases: The Missing Keystone of Universal Health Coverage”, 2019.

⁴² See www.ema.europa.eu/en/human-regulatory/overview/orphan-designation-overview.

⁴³ Committee on Economic, Social and Cultural Rights, general comment No. 24 (2017) on State obligations under the International Covenant on Economic, Social and Cultural Rights in the context of business activities, para. 20.

⁴⁴ *Ibid.*

⁴⁵ See www.transparency.org/topic/detail/health; see also A/72/137, para. 12.

⁴⁶ Subrata Chattopadhyay, “Corruption in healthcare and medicine: Why should physicians and bioethicists care and what should they do?”, *Indian Journal of Medical Ethics*, vol. X, No. 3 (July–September 2013), p. 154.

many forms in the health sector: bribery, absenteeism, improper marketing relations, misuse of (high-) level positions, informal payments and induced demand.⁴⁷

VI. Applying key human rights principles to universal health coverage

32. In line with the character of the right to health as an inclusive right comprising the underlying determinants of health,⁴⁸ universal health coverage should be understood as incorporating effective access, health promotion, disease prevention and other determinants of health, as well as “formal” coverage. A narrow focus on population coverage tends to favour curative services; and, as seen in the case of non-communicable diseases, health promotion and disease prevention are vital components of an effective response. Although States enjoy a margin of discretion when deciding how universal health coverage is to be achieved, human rights principles should guide the formulation, implementation, monitoring and review of policy in this area, as well as in ensuring accountability. In the section below, the High Commissioner outlines how they are relevant to universal health coverage.

A. Levels of obligation

33. States have a duty to respect, protect and fulfil their human rights obligations. Under the right to health framework, the obligation to respect requires States to refrain from interfering directly or indirectly with the enjoyment of the right to health, the obligation to protect requires measures to prevent third-party interference, and the obligation to fulfil requires States to take appropriate measures towards the full realization of the right to health.⁴⁹

34. Similar obligations apply to the right to social security: respecting the right to social security involves refraining from engaging in any practice or activity that, for example, denies or limits equal access to adequate social security;⁵⁰ protection requires, for example, taking measures to restrain third parties from denying equal access to social security schemes operated by them or by others and imposing unreasonable eligibility conditions; and fulfilling calls for measures to ensure the full realization of the right to social security, such as the implementation of a social security scheme. Although ensuring universal health coverage primarily entails the obligation to fulfil both rights, the duties to respect and to protect have an important application when, for example, regulating the promotion of harmful products by private sector entities, regulating private sector influence on access to essential medicines and other health services and goods, or eliminating discrimination in access to health care.⁵¹

B. Maximum available resources and progressive realization

35. Article 2 (1) of the International Covenant on Economic, Social and Cultural Rights places a duty on States parties to use their maximum available resources towards achieving progressively the full realization of the rights recognized in the Covenant. “Maximum available resources” refers to both the resources existing within a State and those available through international cooperation and assistance, and has policy implications both for raising revenue and for government expenditure (see E/2017/70).⁵² In this respect, taxation is widely considered to be one of the most significant and predictable sources of revenue available to governments, and is vital for redressing systemic discrimination, ensuring the equal

⁴⁷ European Commission, *Updated Study on Corruption in the Healthcare Sector*, 2017, pp. 9 and 37.

⁴⁸ Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) on the right to the highest attainable standard of health, para. 12.

⁴⁹ *Ibid.*, para. 33.

⁵⁰ Committee on Economic, Social and Cultural Rights, general comment No. 19 (2007) on the right to social security, para. 44.

⁵¹ *Ibid.*, paras. 50–51; see also Committee on Economic, Social and Cultural Rights, general comment No. 19, para. 45.

⁵² See also E/C.12/2007/1, para. 5.

enjoyment of economic, social and cultural rights and funding essential services, social protection and poverty reduction measures (A/HRC/26/28, paras. 3, 17 and 36). While States may determine their own fiscal policies, human rights obligations impose limits on the exercise of that discretion, and they must be allowed to guide fiscal policies in order to ensure that States respect, protect and fulfil human rights (*ibid.*, para. 4).

36. Progressive realization requires States immediately to take concrete, targeted and deliberate measures to achieve the realization of economic, social and cultural rights.⁵³ There is a strong presumption that retrogressive measures are unlawful. Where these have been taken, the State must establish that they have been introduced after the most careful consideration of all alternatives and that they are duly justified by reference to the totality of the rights provided for in the Covenant in the context of the full use of the State party's maximum available resources.⁵⁴ Fiscal consolidation measures, such as austerity policies, a distinguishing feature of which is often a reduction in social sector spending, are therefore presumed to be unlawful (see E/2013/82).

C. Right to health and right to social protection

37. Under article 12 (2) of the International Covenant on Economic, Social and Cultural Rights, the full realization of the right to health requires several measures, including (a) the provision for the reduction of the stillbirth-rate and of infant mortality, and for the healthy development of the child; (b) improvement of all aspects of environmental and industrial hygiene; (c) the prevention, treatment and control of epidemic, endemic, occupational and other diseases; and (d) the creation of conditions which would assure to all medical service and medical attention in the event of sickness. The human rights-based approach derived from these norms requires national governments to ensure that health facilities, goods and services are available in sufficient quantity and are physically accessible and affordable on the basis of non-discrimination. They should also be scientifically and medically appropriate, of good quality, and respectful of medical ethics.⁵⁵ Participation and accountability are indispensable features of the right to health.

38. The right to social security encompasses the right to have access to and maintain benefits (whether in cash or in kind) without discrimination, in order to secure protection in the event of (a) lack of work-related income caused by sickness, disability, maternity, employment injury, unemployment, old age or death of a family member; (b) unaffordable access to health care; and (c) insufficient family support, particularly for children and adult dependents.⁵⁶ Cash or in-kind benefits should be adequate in amount and duration to facilitate the realization of the rights to family protection and assistance, an adequate standard of living and adequate access to health care.⁵⁷ Essential health care (including access to health facilities, goods and services on a non-discriminatory basis, provision of essential drugs, access to reproductive, maternal and child health care, and immunization against the major infectious diseases) is part of the core content of the right to social security.

39. The protection of the right to health is a prerequisite for the enjoyment of other human rights, especially those necessary to safeguard dignity, assert autonomy and realize potential. Reflecting the interrelatedness and indivisibility of human rights, the converse is also true: the right to health can only be fully realized when other human rights, particularly the rights to social security, adequate housing, water and sanitation, participation, freedom from discrimination, education and information and food are upheld. The right to social security, in particular, secures the enjoyment of at least the minimum core content of economic and social rights, such as the rights to health and food, against risks and contingencies throughout the life cycle, and is extremely important in the context of endemic diseases, such as HIV/AIDS, tuberculosis and malaria.⁵⁸ A comprehensive social protection system helps to

⁵³ Committee on Economic, Social and Cultural Rights, general comment No. 14, para. 30.

⁵⁴ *Ibid.*, para. 32.

⁵⁵ *Ibid.*, para. 12.

⁵⁶ Committee on Economic, Social and Cultural Rights, general comment No. 19, para. 2.

⁵⁷ *Ibid.*, para. 22.

⁵⁸ *Ibid.*, para. 13.

address the multiple dimensions of deprivation and hardship linked to illness, such as accessibility of medical care, related non-medical expenses, such as transportation, and loss of income or time due to absence from work. Treating other human rights, including the right to social security, as determinants of the right to health facilitates the formulation of comprehensive, whole-of-government policies involving all sectors that affect health.

D. Equality and non-discrimination

40. Although the aspiration of universal health coverage is equality and inclusion, the reality is that access to good quality health services, goods and facilities is determined by, among other things, wealth, privilege, influence, marginalized status, identity and place of residence. The existence of striking inequalities in access to health care and services in some of the wealthiest countries, contrasted with the success of other countries in extending coverage despite their resource-poor settings,⁵⁹ strongly suggests that policies affecting health coverage are frequently political choices that are not necessarily or consistently informed by the resources actually or potentially available for health.

41. States have a special obligation to provide those with insufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds in the provision of health care and health services, especially with respect to the core obligations of the right to health.⁶⁰ Core obligations, such as the provision of essential medicines and the equitable distribution of all health facilities, goods and services and access to health care and services on a non-discriminatory basis, engage the immediate responsibility of the State and are subject to neither progressive realization nor derogation.⁶¹

42. Non-nationals should therefore be able to have access to non-contributory schemes for income support, affordable access to health care and family support. All persons, irrespective of their nationality, residency or immigration status, are entitled to primary and emergency medical care. Refugees, stateless persons and asylum seekers, and other disadvantaged and marginalized individuals and groups, should enjoy equal treatment in access to non-contributory social security schemes, including reasonable access to health care and family support, in accordance with international standards.⁶² Failure to take measures to reduce the inequitable distribution of health facilities, goods and services, and insufficient expenditure or the misallocation of public resources, resulting in the non-enjoyment of the right to health by individuals or groups, particularly vulnerable or marginalized persons, are examples of violations of the right to health.⁶³

E. Participation

43. The right to participate in public affairs is vital to the enjoyment of other human rights. It is a democratic imperative that has the aim of ensuring that all voices are represented where public decision-making is called for. Under the rights to health and to social security, all stakeholders should be empowered to participate at all stages where policy is designed, set, implemented, monitored and reviewed. Human rights-based budgeting, for instance, requires transparent processes and mechanisms involving the participation of affected communities, and coordination among a variety of government ministries and departments, and with other key actors, such as the private sector, development partners and civil society (see A/HRC/21/22 and Corr. 1 and 2, para. 52).

⁵⁹ See assessment by ILO on the situation in Rwanda (www.ilo.org/wcmsp5/groups/public/---dgreports/---integration/documents/publication/wcms_568702.pdf) and Thailand (www.ilo.org/wcmsp5/groups/public/---dgreports/---integration/documents/publication/wcms_568679.pdf).

⁶⁰ Committee on Economic, Social and Cultural Rights, general comment No. 14, para. 19.

⁶¹ *Ibid.*, paras. 30, 43 and 47.

⁶² *Ibid.*, general comment No. 19, paras. 37 and 38.

⁶³ *Ibid.*, general comment No. 14, para. 52.

44. Participation provides important oversight, particularly when identifying priorities and preventing policy trade-offs that may be detrimental to health coverage. Health promotion, especially, must involve the meaningful participation of rights holders at the community level in order to be effective.⁶⁴ In accordance with the obligation to include marginalized and vulnerable members of society, such as children, adolescents, persons with disabilities and people living in poverty, the participation of these persons should be ensured and their views explicitly considered and given priority in matters exclusively concerning each group.⁶⁵ Given the lack of consensus around priority-setting in health service delivery, health coverage is an area where stakeholder participation, especially at the community level, is essential.

F. Accountability

45. As emphasized by the High Commissioner in a previous report, accountability is a complex, multidimensional concept, and human rights-based accountability requires numerous forms of review and oversight, and the fostering of the accountability of multiple actors at various levels, both within and beyond the health sector (A/HRC/38/37, para. 37). Accountability cuts across all areas of policy design, implementation, monitoring and review. As affirmed by the High-level Working Group on the Health and Human Rights of Women, Children and Adolescents in its report (see para. 19 above), strengthening accountability as a core pillar of good governance and in fulfilment of duty bearers' obligations to rights holders offers important opportunities for the realization of health and human rights. Establishing strong accountability mechanisms and processes in the area of health coverage ensures that policy measures, including health financing, measures to eliminate discrimination and inequalities, and measures to counter corruption remain closely linked with the objective of extending universal health coverage. Crucially, accountability demands the availability of readily accessible avenues of redress (judicial or quasi-judicial) where breaches of the right to health or the right to social security have been committed.

VII. Conclusions and recommendations

A. Conclusions

46. **Different stakeholders involved in the implementation of universal health coverage emphasize different priority areas. Nevertheless, a consensus appears to be emerging around a number of elements, among others, as essential to universal health coverage: primary health care; palliative care; a nationally defined set of goods and services; maternity care; emergency treatment; access to medicines; attention to structural and social inequalities, to the needs of the marginalized and vulnerable, and to discrimination; financial risk protection; health promotion; and disease prevention.**

47. **Human rights norms stress availability, accessibility, acceptability and good quality of health services, facilities and goods. They also provide clear guidance on the meaning of universality, namely, that access to health care and services should not be limited to those who are able to pay or to those who benefit from employer-based schemes in the formal labour market. The principle of non-discrimination applies to universal health coverage, and its protection is available for non-nationals, such as migrants in an irregular situation, and for groups and populations that are usually excluded, such as older persons, persons living in poverty, persons with disabilities and persons living with rare diseases.**

⁶⁴ See Joint United Nations Programme on HIV/AIDS (UNAIDS), "Non-discrimination in HIV responses", 3 May 2010, paras. 18–22.

⁶⁵ Convention on the Rights of Persons with Disabilities, art. 4 (3); Committee on the Rights of Persons with Disabilities, general comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention.

48. Universal health coverage is not merely a financial, economic or development concern; it is a matter of social justice and equality, and of realizing all the health-related human rights the enjoyment of which is essential to human dignity and the right to life. The challenges of implementing universal health coverage are diverse and complex, affecting the multiple rights of millions of people and requiring policies that are “fit for purpose”. In human rights terms, this means embracing an understanding of universal health coverage that encompasses the underlying determinants of health. It also demands political leadership, including at the highest levels, to bring about the changes that must precede the reorientation of public health policy towards human rights-compliant models of universal health coverage. This leadership would shepherd policy changes in a whole-of-government approach, in partnership with an empowered, informed and engaged stakeholder base.

49. In the light of the above conclusions, the High Commissioner makes the recommendations below.

B. Recommendations

50. Given that laws, policies and practices determine the extent to which human rights, including the rights to health and to social security are enjoyed, States should conduct regular reviews of their legal and policy frameworks to identify gaps in health coverage and social protection, of barriers to access to health services, and of the extent to which these frameworks are in conformity with the right to health, the right to social security and other health-related rights. Such reviews will assist in identifying populations that are being left behind, the factors behind their marginalization, the impact of corruption and the structural, administrative, legal and social determinants of health.

51. States should, on the basis of a comprehensive human rights analysis as outlined above, amend their laws and policies to respond to the human rights deficits identified during the course of the analysis and to align them with international human rights standards. States should ensure, in particular, that the legal and policy framework addresses discrimination in access to health care and services, ensures effective access to medicines, therapies and technologies for all persons without discrimination, and protects the rights of persons living with rare diseases, migrants in an irregular situation, persons with disabilities and other vulnerable groups, including through the use of special measures where appropriate.

52. Universal health coverage should be explicitly provided for through legislation that mainstreams the rights of persons with disabilities. Effective legislation is founded on human rights principles; it also acknowledges the role of various duty bearers at the governmental level, assigns responsibilities, recognizes rights holders and their entitlements, addresses discrimination in health coverage, prioritizes community participation, and ensures the robust regulation of the private sector, in accordance with the Guiding Principles on Business and Human Rights.

53. States should adopt national plans and strategies for the progressive realization of the rights to health and to social security that mainstream universal health coverage in both the health and social security sectors with a view to ensuring comprehensive coverage for all, without discrimination.

54. The High Commissioner recommends that States, in the area of universal health coverage:

- (a) Ensure the participation of stakeholders in priority-setting, policy and programme design, implementation, monitoring and evaluation;
- (b) Build the capacity of rights holders to participate and to claim their rights to health coverage through education and awareness-raising;

(c) Ensure that transparent and accessible mechanisms for engaging the participation of stakeholders are established and strengthened at the community, subnational and national levels.

55. The High Commissioner encourages States, in order to ensure independent accountability:

(a) To establish and/or strengthen transparent, inclusive and participatory processes and mechanisms, with jurisdiction to recommend remedial action within both the health and the justice systems;

(b) To develop national strategies to promote access to justice mechanisms, and to ensure accessible proceedings and the provision of procedural accommodations for persons with disabilities;

(c) To ensure effective access to remedies and redress for violations of the rights to health and to social security and other health-supporting rights.

56. States should mobilize available international resources and provide support in conformity with the duty of international cooperation. The High Commissioner urges them, in partnership with relevant international and regional organizations, civil society and local communities:

(a) To seek technical support for the design and implementation of programmes and policies to strengthen and expand health coverage, to ensure quality service delivery, and to promote financial risk protection for marginalized groups and communities, including persons with disabilities, migrants and others;

(b) To support capacity-building, including through training programmes and the sharing of information, experiences and good practices in extending health coverage in resource-poor settings;

(c) To cooperate in ensuring continuity of care for migrants, particularly migrants in an irregular situation;

(d) To share technical expertise and good practices for health workforce strengthening, particularly with a view to ensuring just and favourable conditions of work, addressing health and care worker migration, and providing training, including in human rights.

57. The High Commissioner urges States to align their fiscal policies and planning and budgeting processes with human rights principles in order to ensure the efficient use of the maximum available resources for the equal enjoyment of the rights to health and to social security.

58. Member States should adopt a broad approach to universal health coverage, embracing human rights principles and standards as highlighted in the present report. The High Commissioner encourages them to give consideration to developing, with the support of the Office of the High Commissioner and other stakeholders, a set of guidelines on universal health coverage and human rights with a view to supporting the implementation of a human rights-based approach to universal health coverage. On the basis of such guidelines, the Office of the High Commissioner envisages reviewing practices at the State level in order to assess the extent to which States are meeting their obligations to ensure universal health coverage, and supporting the exchange of good practices in this regard.